

## Respite and Short Breaks Consultation Joint Health Scrutiny Committee

### Consultation Response

11 January 2018

1. A statutory Joint Health Scrutiny Committee was established to develop a response to the Respite and Short Breaks consultation on behalf of its constituent councils (Stockton-on-Tees, Hartlepool, Middlesbrough, and Redcar and Cleveland). The Committee was chaired by Cllr Grainge (Stockton-on-Tees BC), and the vice-chair was Cllr Jeffrey (Redcar and Cleveland BC).
2. The Joint Committee has considered the consultation information provided by the CCGs including the public consultation documents, the case for change, feedback from Adult Social Care, stakeholders including local MPs, and heard directly the views from parents and carers of clients of Bankfields and Aysgarth. At its meeting on 14 December, the Joint Committee was provided with the results of the Public and Stakeholder consultation.
3. Following the consultation process, the significant concerns of the parents and carers of current users of the service have been recognised by all parties on the Joint Committee.
4. It is recognised that there has been both a pre-engagement process and a formal consultation process, however concerns remain surrounding how the options were articulated to parents/carers and clients.
5. A major issue during the consultation was the need to better communicate what the form of alternative community-based services would look like in future and where they would be based, to enable an informed decision to be made. A high level summary of this type of provision was provided by the CCGs and included: overnight bed-based care (eg.in a care home, shared lives settings, or adapted accommodation), support in own home, support to access community, holiday and short breaks, transport provision, and supported by clinically-led outreach support where necessary.
6. Further information on this was provided during the consultation process, and case studies were provided to the Joint Committee. However it was clear that further reassurance on this issue was needed for parents and carers, and this continues to be the case. There were a number of issues raised, including, for example, that environments such as care homes may not be age appropriate.
7. Irrespective of the form that alternative services may take, there is a clear view that community based services would not be suitable for many of the clients with high levels of complex needs. There are also concerns about the quality of alternative provision and how this would be monitored.
8. There are clearly concerns over the possibility of a 'downgrade' in service provision. The current service is recognised as providing a very good level of care and has the ability to meet the high level and complex needs of the clients.

9. A significant benefit of the current facilities is that they are dedicated to this level of provision. The service provides continuity of care for clients, some of whom have been receiving the service over a long period of time and have developed strong relationships with the staff.
10. It is recognised that there is a desire for greater flexibility and choice in local respite services, and recognition that children and young people coming through into adulthood do have different needs and expectations of the options that should be available. But there is a strong view that this should not be at the expense of current provision.
11. As part of Option 2, it was outlined that an element of current service provision would be retained, alongside the development of community-based provision, within the same amount of overall funding. The balance between spend on current and possible alternative provision was not fully articulated, and so there is an assumed level of reduction in current services to some extent, within Option 2 as presented.

**The specific views of each Council for consideration by the CCGs are as follows:**

**Stockton-on-Tees BC**

12. The Council notes that of the two services under review, the majority of Stockton-based service users attend the Aysgarth service in Durham Lane. Current usage shows that Aysgarth is accessed by 38 people from Stockton, and 2 from Hartlepool (as of September 2017). Stockton-based clients have occasionally used Bankfields Court but this primarily serves the Middlesbrough and Redcar areas.
13. The Council would have major concerns should provision cease completely at Aysgarth and/or Bankfields due to the concerns about access to, sustainability, and resilience of local learning disability care, summarised as follows:
  - a) there are no other learning disability nursing facilities in the Stockton Borough area in the independent sector
  - b) assurances have been given from potential alternative providers as part of market engagement, however these were not yet tested in an area of what is very specialist provision. Complete closure of current facilities would therefore present a considerable risk. There are well known concerns in relation to pressures on nursing staff availability in the local health sector.
  - c) the general presumption of local authorities is to keep people as close to home as possible. Should alternative services be based outside of the Borough for some clients, there would be issues surrounding their transport/travel support needs, and whether carers were receiving true respite.
  - d) currently users of Aysgarth are funded via the NHS for the respite services they receive there, due to their assessed level of identified complex and health needs. A shift to increased community-based provision may lead to an increase in cost to the local authority and this aspect has not been fully explored.
  - e) it is recognised that there is commitment to retain the overall budget for this service area, however there needs to be a commitment to meeting identified eligible health

needs. There is an opportunity to change services and expand the range of flexible, more community based services for those clients that choose to access them. However this needs to be properly funded, and there is concern over whether the amount is actually enough to meet identified need across the client group as a whole, and the total amount allocated should be kept under review.

f) the Local Authority requests substantial assurances with regard to the quality of any future alternative services, should they be developed, particularly in the first crucial six months to a year. Transition to alternative services would need to be carefully managed and staged over whatever time period is appropriate, on a client by client basis.

14. There are a number of clients in Stockton who have autism and for whom Aysgarth is not suitable. These clients currently receive services outside of the Borough at significant cost. There is therefore the potential to develop alternative services for this group.
15. A revised approach to assessment and allocation criteria would be welcomed, as these need to better reflect actual need.
16. The Council recognises that this process has now been ongoing for some time (including the periods of pre-engagement and formal consultation) and there is a need to provide some certainty for the clients, parents and carers. Any future development of services needs to be through a process in which all sides are fully engaged.
17. In summary, the Council would support the retention of current services. However if a decision was to be made, Option 2 would be preferable, subject to satisfactory resolution of the above concerns.

### **Redcar and Cleveland BC**

18. At their meeting on 24 October 2017, Members of Redcar and Cleveland's Adult and Communities Scrutiny & Improvement Committee invited representatives from the CCG to discuss their options for respite opportunities and short breaks that were the subject of their consultation. These services are currently delivered through bed based provision at two locations; 2 Bankfields Court, Normanby (within the borough of Redcar and Cleveland) and Aysgarth, Stockton.
19. As at October 2017, 51 people from the Middlesbrough and Redcar and Cleveland localities were regularly accessing services from Bankfields Court. Seventeen of these were from Redcar and Cleveland.
20. A parent carer of a service user from Bankfields Court also addressed the Committee and Members heard that the current levels of service provided at the facility were excellent; meeting the both the complex learning disability and medical needs of the individual and enabling the parent to feel reassured and confident about the care provided and to benefit from the respite opportunity.
21. The bed base was considered to be a critical and valuable aspect of the current service offer, particularly given the medical needs of many of the service users. The

consultation referred to providing alternative respite opportunities and it is clear that there is a desire to provide greater flexibility and choice for children and young people reaching adulthood, however, the lack of clarity regarding what that alternative provision might be was a major concern. This lack of clarity undermined the value of the consultation exercise as respondents were unable to form a view about the undefined aspects of the proposals.

22. The current client base was small enough to warrant individual consultation but this had not been done and as such, it was felt that the consultation exercise was flawed.
23. Recent national media coverage indicated that similar reviews were taking place across the Country, resulting in similar response from client groups. This raised concerns that there was perhaps some national agenda to make changes to provision of respite services.
24. In line with the Joint Committee's recommendation, the Council:
  - a) does not support either of the options being put forward
  - b) recommends that the CCGs should retain the current level of service provision at Bankfields and Aysgarth.

### **Middlesbrough BC**

25. On the 19 December 2017 the Health Scrutiny Committee, as the body responsible for Middlesbrough's statutory health scrutiny function, received an update in relation to discussions at the Respite Opportunities and Short Breaks Consultation Joint Health Scrutiny Committee held in Stockton on 14 December 2017. The update, provided by our representatives on the Committee, informed Middlesbrough Health Scrutiny Panel's view on the consultation.
26. In light of the evidence received Middlesbrough's Health Scrutiny panel wishes to submit the following response to the consultation:
  - i) In line with the view expressed by the Joint OSC the panel is not supportive of either of the options being put forward.
  - ii) The panel recommends that the CCGs should retain the current level of service provision at Bankfields and Aysgarth.
27. The reasons for the above are as follows:
28. From the evidence presented it is clear that although the CCGs have undertaken a consultation exercise, no shared understanding of the respite needs of those affected has resulted. In light of this and the palpable strength of difference in opinion between the CCGs and the family carers in respect of the bed based respite needs of those with 'profound and severe' learning disabilities, the panel cannot support either of the options. Neither proposal is viewed by the panel as appropriate for adequately meeting the needs of the individuals currently in receipt of the service. In addition to future projected demand.
29. Under the Care Act 2014 the NHS and Adult Social Care has a statutory duty to ensure that the needs of carers are being met.

30. When hearing directly from Middlesbrough family carers the following points were made:-
- a) Some of the people accessing bed based respite at Bankfields are at the extreme end of the autism spectrum, they have coexisting complex health needs including profound and multiple disabilities, complex epilepsy, mental health conditions and challenging behaviour. They also include adults with profound and multiple learning disabilities who have additional health needs. The CQC has recognised that there is good practice being evidenced at Bankfields and Aysgarth and people are protected from any risk of abuse. The CQC recognises that there is evidence of good practice at Bankfields and Aysgarth, and carers are confident that their sons and daughters are medically and emotionally cared for and are safe from any risk of abuse. Carers value the consistency of care provided and are reassured that the staff are highly skilled and aware of the individual needs of the adults in their care.
  - b) Bankfields was refurbished recently to make it an even more bespoke facility in terms of the offer it provides is for clinical respite care. Given that the current provision at Bankfields provides clinical oversight, carers have peace of mind, and confidence. To access bed based respite at Bankfields and Aysgarth, individuals are assessed against criteria that the individual requires 24 hour access to nursing interventions. Under the current provision the monitoring of both clinical and safeguarding aspects of care are in one place.
  - c) The public consultation documentation is misleading and gives the impression that the individuals affected would regularly be able to partake in short break opportunities. The reality is that the level of complexity of need and the requirement for clinical oversight for many of those affected would make this extremely difficult or impossible e.g. many are non-verbal, are unable to take part in consultation or conversations, have specially adapted wheelchairs to support their bodies, wheelchairs designed and used to prevent their internal organs from being damaged, sleep systems for night time posture and some also need to be PEG tube fed.
  - d) At the end of the 2 hour public consultation event held in Redcar and Cleveland each table was afforded the opportunity to ask 1 question, with only a 15 minute period allocated for questions. Given the level of need and complexity of each of the 94 individuals accessing bed based clinical respite provision at Bankfields and Aysgarth better engagement with the families directly affected could have been undertaken.
31. The proposals present 2 options and although 90 per cent of respondents have indicated a preference for option 2 - it is the panel's view that neither option is what those affected, their family carers or Members want as an outcome. The panel is firmly of the view that the current level of service provision at Bankfields and Aysgarth needs must be maintained as a matter of priority and the panel cannot therefore support either option.
32. Throughout the consultation process the panel has been repeatedly advised that the service provision provided at Bankfields and Aysgarth is regarded as 'gold standard' provision. Inspection reports from the CQC on both facilities highlight the good practice in place by the current provider Tees, Esk and Wear Valley NHS Foundation Trust. It would be remiss of this panel, if it did not do everything within its power to protect this service which benefits the most vulnerable adults in Middlesbrough. Both of the options in their current form would result in a reduction in the provision of bed based respite at

Bankfields and Aysgarth, which the panel does not believe to be in the best interests of those affected.

33. Reference is made in the consultation report to the fact that there will be a new needs led assessment and allocations process which will change how resources are allocated. This was not made explicit to those currently receiving services during the consultation process and understandably there are real concerns that proposed changes in the eligibility criteria will result in some people no longer being able to access bed based respite. The shift in assessment criteria to take into consideration, for example, the nutritional needs of individuals is similar to the criteria considered in the Continuing Health Care (CHC) assessment and raises concerns about the potential for these changes to result in a reduction in the number of people eligible to receive bed based respite. The consultation findings clearly highlight that overnight bed based respite is considered the most important element of respite care by carers from the list of possible flexible community based respite services.
34. The CCGs have acknowledged that there are currently people who are unable to access bed based respite and there is a need to ensure that the £1.5 million funding the CCG has allocated for health based respite is spent in a better and more appropriate way. However, the CCG's have been unable to evidence the amount spent on health respite provision over the last three years. The panel is fully supportive of new opportunities being developed for those additional people in need of bed based respite but not at the expense of those currently in receipt of this provision. Members are firmly of the view that it would be better to expand the service and make it more efficient rather than decommission or reduce the current 11 bed based clinical respite offer currently provided at Bankfields and Aysgarth.
35. In terms of the safeguarding concerns raised throughout this process the panel has yet to be satisfied that these issues have been addressed. It has been highlighted by Adult Social Care that there is a lack of learning disabilities nursing provision within the independent sector locally and therefore any potential providers of community bed based respite provision remains untested. The panel is of the view that this presents a considerable risk in a very specialist area.
36. Finally and perhaps most importantly the aim of respite provision is to afford those family carers, who provide 24/7 hour care 365 days a year for their family member with profound and severe needs the opportunity to 'recharge their batteries'. The panel is of the view that the 'voice of the carer' has not been fully taken into account during the consultation and the attendance of in excess of 40 family carers and their sons and daughters at a meeting of the Joint OSC in November was testament to the fact that many felt their concerns had not been listened to and their voices had not been heard.
37. Ultimately, the primary aim of health scrutiny is to strengthen the voice of local people and ensure their needs and experiences are considered as an integral part of the commissioning and delivery of health services and that those services are effective and safe. On the basis of the above, Middlesbrough's Health Scrutiny panel's wish is that neither of the 2 options presented be progressed and that further collaborative work is undertaken to reach a consensus view on the best way forward.
38. This view is supported by Middlesbrough's Executive Member for Adult Social Care and Health Integration.

39. Hartlepool Borough Council supports fully the ethos of equity of provision for all those who require respite services and the need to improve / expand existing services. The continuation of existing 'excellent' services from Bankfields and Aysgarth is critical to this and on this basis we agreed with the recommendation of the Respite Opportunities and Short Breaks Consultation Joint Health Scrutiny Committee, that
40. The consultation response should:
  - a) not support either of the options being put forward
  - b) recommend that the CCGs should retain the current level of service provision at Bankfields and Aysgarth.
41. In addition to this, we reiterate the concerns expressed by Hartlepool's Audit and Governance Committee, and Adult Services Committee (11 December 2017 and 6 December 2017 respectively). We continue to feel strongly that the consultation is flawed and these concerns were not resolved by the consultation update given to the Respite Opportunities and Short Breaks Consultation Joint Health Scrutiny Committee on the 14 December 2017. On this basis, should the CCG Governing Body in Common, on the 1 February 2018, reject the recommendations of the Respite Opportunities and Short Breaks Consultation Joint Health Scrutiny Committee, we maintain our insistence that any decision regarding the future of this service be delayed pending completion of a full, and effective, consultation process that enables all interested parties (with particular emphasis carers and families of those who have, or have tried to access the service) to have the fullest possible opportunity to express their views.

### **Next Steps**

42. A meeting of the Joint Committee has been arranged for 5 February 2018 in order for Members to consider the decisions made by the CCGs.